DOCUMENT RESUME

ED 252 049 EC 171 306

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TITLE Brokering Power at the State Level for Child Health Care. Workbook Series for Providing Services to Children with Handicaps and Their Families.
INSTITUTION Georgetown Univ. Child Development Center, Washington, DC.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE May 84
GRANT DHHS-PHS-MCJ-113368-01
NOTE 34p.; For related documents, see EC 171 305-308.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Child Advocacy; Community Programs; *Decision Making; *Disabilities; Diseases; *Financial Support; *Political Influences; *Political Power

ABSTRACT

The workbook is intended as a primer for public and private sector state level advocates for children with disabilities and chronic illnesses. It is designed to give practical guidance on how to intervene effectively in the legislative and executive appropriation and budget processes. The first section examines the role of the partners-in-power: the legislative, judicial, and executive branches and the advocate/power broker. Examples of problems, desired approaches, desired outcomes, and the partners-in-power needed to implement the outcomes are offered. Suggestions center on the following steps: getting the partners-in-power together, getting support from a majority of one's partners, networking, and brokering power. Appended materials include a powerbroker's case study by G. Schiebler and S. Freedman, "Regionalized Neonatal/Perinatal Intensive Care Center Program: A Political History." (CL)

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BROKERING POWER AT THE STATE LEVEL FOR CHILD HEALTH CARE

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EC171306

WORKBOOK SERIES FOR PROVIDING SERVICES TO

CHILDREN WITH HANDICAPS AND THEIR FAMILIES

BROKERING POWER AT THE STATE LEVEL

FOR CHILD HEALTH CARE

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Edited by the editorial staff of the National Center for Education in Maternal and Child Health

May, 1984

EC171306

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INTRODUCTION

Power-brokering for financing of comprehensive care for children with disabilities and chronic illnesses is a challenge to advocates in both the public and private sectors. Competition for resources is always intense, and whether your competition is a program in education or a road construction project, you can be assured of only one outcome--if you don't compete, you can't succeed. This special form of advocacy requires creativity, energy, and a willingness to take risks. The brokering of power within and among branches of state government must be viewed as a long-term enterprise with a unique set of values. This process can be as genteel as a society tea or as brutal as a wrestling match, but implicit rules always exist and these rules vary with the nature of the contest.

This workbook is intended as a primer for public and private sector advocates at the state level. Its focus is power-brokering at that level for support of programs for the care of children with disabilities and chronic illnesses. It is not intended to be a grantsmanship manual, but rather to give practical guidance on how to intervene effectively in the legislative and executive appropriation and budget processes on behalf of care for the children for whom you chose to advocate.

It is important to understand that power-brokering is politics and that politics is a process which you own. Honesty, commitment, cooperation, and knowledge are the most useful tools in making the process work. Politics is a neutral value; your values and the values expressed by your efforts define the quality of that process.

This workbook is intended to:

* Help you identify the key players in state government;

* Suggest ways to develop your issue for consideration;

* Indicate strategies for gaining support for your issue; and

* Provide information regarding the use of appropriate influence.

Whether you are a state official/employee or a community level advocate, you should view the power-brokering process described in this workbook as a worthwhile and significant commitment, not a casual interest. Power-brokering is for the dedicated, not the dilettante.

PARTNERS-IN-POWER--LEGISLATIVE, EXECUTIVE, JUDICIAL AND YOU A DIVISION OF LABOR

Legislative Branch

The role of the legislature is to set policy for the state, to assure that sufficient resources (appropriations) are available to implement those policies and to review and evaluate the impact of the policies and the appropriations to assure that those impacts are the ones originally intended. One policy-making function of the legislature is the establishment, through statute, of programs of care for children with disabilities and chronic illnesses. You elect members of the legislature to serve two principal functions. First, they must represent you and other citizens of your community to assure that state policy is of benefit to your local interests. Second, they assist each other in establishing policies which are benefitting the citizens of the state as a whole. They cannot properly fulfill either of these important functions without your input and feedback.

REMEMBER:

Legislative policy making cannot reflect your point of view unless you express it to one or more legislators.

Executive Branch

The executive branch designs programs to implement the policies established by the legislature and to manage the resources provided in

support of those policies. The executive branch also monitors its programs and provides feedback to the legislature on the implementation of the programs and use of resources. The feedback provided to the legislature by the executive branch supplements your own feeuback.

Officials and employees in the executive branch are appointed to serve the best interests of the state as a whole. They also need your input and feedback. However, unlike your legislators, executive branch officials and employees are not directly accountable to you. When executive branch agencies carry out their responsibility to implement programs, numerous opportunities arise for advocate involvement. The agency is typically required to develop plans, guidelines, and administrative rules and budgets to govern the implementation of each program. You can have influence on the development of such governing documents as they are being developed. You are certainly entitled to review and comment on them after they are drawn up.

REMEMBER:

If you say or do nothing, it will be assumed you agree with the way in which a program is implemented.

Judicial Branch

The state judiciary decides in disputes relating to state policy. Where unresolved differences of opinion about state policy exist between citizens and an agency, one agency and another, or the legislative and executive branches, the state judiciary may make a binding decision. The state court typically will not get involved in a dispute until all other official methods of resolving the issue have been exhausted. Consequently, the court has the power to review policy, to mediate between the creators and the implementors of policy, and to assure rights of taxpayers and recipients of public services.

REMEMBER:

You have the right to help make and review state policies and programs; the court can help you exercise that right.

Advocate/Power-Broker

The advocate/power-broker in state government identifies and translates need for programs and policies, assesses the appropriateness and adequacy of programs, identifies problems surfacing with their implementation, and influences the behavior of each of the three other partners. A well-informed and committed advocate/power broker serves a communication function which is both supportive and evaluative of the performance of each of the branches of government; that role can have substantial influence.

REMEMBER:

As an advocate/power-broker for the care of children with disabilities, you are the only partner who has that interest, full time. The children must rely on you, full time.

GETTING THE PARTNERS-IN-POWER TOGETHER: THE ISSUE

Advocacy and power-brokering are different in the same way that a shotgun is different than a rifle. The first is aimed at a broad area; the second is aimed at a single point. As an advocate for children's health care you generally support better access, more adequate programming, and continually enhanced funding. Your advocacy may even be more focused, e.g., handicapped children, developmentally disabled children, or children suffering from a specific disease. However, power-brokering must be focused at smaller targets like adequate financing of institutional alternatives for ventilator dependent children, or the development of parent training programs for the home management of children with spina bifida. Power-brokering typically focuses on one issue for one group at a time.

You must be clear about what you want so that you can tell your partners-in-power specifically what you expect to see happen, why, when you expect to see it happen, who will benefit from it, what their partner's role is in making it happen, and why they should be interested.

You must genuinely understand the issue in order to do an effective job of brokering for it. Get all the information you can on the subject. It may help to respond to the following set of questions: (Use Worksheet #1 to organize the collection of that information.)

What kind of help is needed?
How many children need help?
Where do they live?
What are the problems they are faced with?
What do parents think about the problems and needs?
What do professionals think about the problems and needs?
Which problems can be solved first with few resources?
Which problems will take large amounts of resources?
How much will it cost to solve the problems?
Which of you partners-in-power can solve the problem?

Once you have the important facts correct, you must refine your issue to express it briefly in both the written and spoken word. Sometimes it helps to use a format of one written page to fully express your issue. (See Worksheet #2) The following is an example of such an issue statement.

EXAMPLE

POWER BROKERS

ISSUE STATEMENT

Desired Outcome

Extend the number of inpatient days per year covered by the Medicaid program from 20 to an unlimited number for children with chronic illnesses.

Problem

Each year for the last three years, approximately 400 chronically ill, Medicaid-eligible children have exceeded the state's limit of 20 inpatient days. This has caused a statewide shift of the cost of that uncompensated care to the local tax base and to the patients with means to pay for such care. The total shifted cost to the local tax base has averaged $3.7 million. This cost is in addition to increased hospital charges and insurance premiums. The extensive inpatient care for these children has been medically necessary so misutilization was not a factor. It is clear that parents of these children are poor, and in addition to coping with their child's medical problems, they are faced with insistent hospital billing notices to which they cannot respond.

Desired Approach

The state should enter into an agreement with local taxing entities to enable them to match their tax revenues with Federal Medicaid funds. Such an agreement would reduce local tax liability for uncompensated care by more than 50%, since the Federal match in Florida is 52%. With the local funds becoming the state match for inpatient hospitalization in the Medicaid program, the day limitation could be ended. Since children are under the E.P.S.D.T. program, inpatient limits may be increased for them without modifying the rest of the Medicaid program.

Partners-in-Power Needed

Both the state Medicaid agency and the state legislature should be involved. The state Medicaid agency would be needed to amend the state plan and rules and to seek Federal approval to permit the extension of the service to children only. The legislature would have to set up an appropriation to permit the use of the funds. Additionally, if existing statutes did not permit the executive branch to take the initiative to structure the desired cooperative funding relationships with local governmental entities, enabling legislation would have to be introduced and passed by the legislature.

The example above is a starting point. Such an example can be used as a "conversation piece" to rally others interested in the issue.

WORKSHEET NUMBER 1

ORGANIZING YOUR INFORMATION

1. What kind of help is needed?

2. How many children need help?

3. Where do they live?

4. What are the problems are they faced with?

5. What do parents think about the problems and needs?

6. What do professionals think about the problems and needs?

7. Which problems can be solved first with few resources?

8. Which problems will take large amounts of resources?

9. How much will it cost to solve the problems?

10. Which of you partners-in-power can solve the problem?

WORKSHEET NUMBER 2

DEVELOPING AN ISSUE STATEMENT

Desired Outcome

Problem

Desired Approach

Participation Required

Additionally, such an issue statement provides an opportunity to draw out the opinion and expertise of both fellow advocates and potential partners-in-power.

REMEMBER:

In power-brokering for an issue, be very specific, avoid the appearance of self-interest, emphasize community benefits, and be open to the opinions and expertise of your partners-in-power.

Ask your partners-in-power to do what they do best. Each has a very special role related to their formal role. An executive branch official cannot change a law or increase an appropriation. An individual legislator cannot require change in eligibilty rules for a state program. A judge cannot initiate legal action in support of program or policy change. It is imperative that you understand and respect their role differences and use those differences appropriately. If you confuse their roles, your partners will become frustrated, irritable, and unresponsive--even if they wish to help.

Assume that your partners want to help and that they will act in good faith. If your issue is well-formed and is perceived as important, achievable, and useful, assume that these are motives of your partners for supporting it. Your efforts must be directed at developing support; not at "converting" your partners to a particular philosophy. Even when support is pledged, don't assume your partners can always do what they promised in support of the issue. There is usually opposition. There is always competition for your partners' attention and for the resources needed to achieve your objective.

REMEMBER:

Ask your partners only for what they can do and understand that they will have other priorities.

GET SUPPORT FROM A MAJORITY OF YOUR PARTNERS

Besides you and your fellow advocates, it is essential to have at least two other partners-in-power. Legislative and executive branch partners are required for any issue objective. Even if the objective can be achieved within one branch, it is important to assure that knowlegeable and willing partners are available in both branches, so that:

* You have two places to be heard and understood;

* You have access to valuable expertise;

* You have multiple sources of feedback on the progress of your issue;

* You create "checks and balances" to assure appropriate pre-, intra-, and post- partum care of your issue.

Choose a few partners-in-power and do it carefully. The number isn't so important as is the right choice. In selecting partners, try to determine who would have reasons to support your issue. In most cases your potential partners are parents or grandparents. Some of them may have children with special needs and, as a consequence, may be particularly sensitive to your issue. In some cases your potential partner may have within his/her constituency a very influential institution or organization which would benefit from the success of your issue. If you know your partners' reasons for supporting your issue, you will have a better idea of how to recruit their support. (See Worksheet #3)

REMEMBER:

Get support from partners from at least two branches and understand how and why your partners are supportive.

WORKSHEET 3

LIST OF POTENTIAL PARTNERS

LEGISLATIVE BRANCH

Key Committee Name _____

(Health, Education, Appropriations, Rules, etc.)

Chairperson

Name _____

Members

Name _____

Name _____

Name _____

Name _____

Name _____

Staff Director

Name _____

EXECUTIVE BRANCH

Agency name _____

(Health, Medicaid, Education, Developmental Disabilities etc.)

Agency head

Name _____

Staff members involved with issue area

Name _____

Name _____

Name _____

Name _____

Once you have recruited your partners, you should be available to them in ways which promote your issue. Let yourself be used as an intercom for your partners. In many cases official relationships between branches of government preclude direct communication. For example, in many states officials of the executive branch are prohibited from initiating direct communication with a legislator, i.e., they are not permitted to lobby. Legislators will avoid direct communication with executive officials to avoid the accusation of the use of undue influence. Both kinds of partners can grow dependent on a reliable intermediary. While serving as that intermediary, you can assure repeated opportunities for attention to your issue. If you are an advocate/power-broker within government, finding a reliable intermediary is essential.

REMEMBER:

Communication is a critical element in the power-brokering process; being integral to that communication is a key to assuring that your issue gets attention.

NETWORKING - KNOWING WHO'S WHO AND WHO KNOWS WHOM

Knowing how to select partners-in-power is as important as defining your issue because without the right support the objective will remain nothing more than rhetoric. Below are some specific questions to answer before selecting your partners:

* What agency in the executive branch is responsible for the program in which you are interested?
  ** Who is the agency's director?
  ** Who are the principal staff of that agency with specific responsibility for that program?

* Which legislative committees would consider your issue?

** Who are the chairs and members of the committees?

** Who are the principal staff persons of those committees?

* What has been the history of those potential partners with issues similar to the one you are proposing?

Once you know who is who, the next step is to identify the people most likely to draw their attention to your issue. These people are called your "key contacts" because they can assist you in presenting and maintaining your partners' attention to your issue. There are several ways to approach the accumulation of information. Most legislatures publish a booklet containing brief biographical sketches of their membership. Typically included in those sketches are items such as church and community organization membership, names of spouses and aides, and college affiliation. If such a document is not available from the legislature, you can find the same information at the offices of any major lobby group, e.g., unions and business or professional associations. For similar information on officials of the executive branch, you may request copies of their resume from the agency with which they are affiliated.

Once you have some idea of the affiliations of your potential partners, you can identify key contacts. As an advocate/power-broker for an issue related to the needs of children with chronic illnesses and disabilities, you should give consideration to developing key contacts with special interest and/or knowledge of your issue, e.g., physicians, hospital administrators, members of child oriented, community organizations.

REMEMBER:

Finding a key contact in your partners' community is extremely valuable. The physician serving the child or grandchild of a potential partner is an excellent key contact.

The following form is an example of how to develop and organize key contact information. (You can use Worksheet #4 for your effort.)

WORKSHEET NUMBER 4

KEY CONTACT INFORMATION FORM

FOR POTENTIAL PARTNER

POTENTIAL PARTNER: Name _____

Office: _____

Phone: _____

Home: _____

Spouse's Name: _____

Children (c) or Grandchildren (g), age:

_____

_____

_____

SPECIAL INTEREST: _____

_____

_____

_____

KEY CONTACT: _____

Office: _____

Phone: _____

RELATIONSHIP TO PARTNER: _____

_____

_____

_____

_____

COMMENTS: _____

_____

_____

_____

_____

EXAMPLE

KEY CONTACT INFORMATION FORM

FOR POTENTIAL PARTNER

POTENTIAL PARTNER: Senator Phyllis Lesser, Chair, Appropriations Sub-committee

Office: 222 Senate Office Building

Phone: 901-555-6666

Home: 1212 Means Way, Middleburg

Spouse's Name: Pincus

Children (c) or Grandchildren (g), age: Ina (c), 7; Ida (c), 4

SPECIAL INTEREST: Nephew (**Samuel**) has cerebral palsy

KEY CONTACT: Daniel Waxman, M.D., Pediatrician
Office: 1984 Recovery Road, Middleburg
Phone: 801-555-2121

RELATIONSHIP TO PARTNER: Second generation of service to Lesser family, Lions Club, Shrine, Yelodim Jewish Temple.

COMMENTS: Dr. Waxman is actively involved with the Middleburg Association for the Developmentally Disabled and is **Samuel's** pediatrician. When contacted, he indicated a willingness to help through his considerable contact with the Lessers. Does not object to contact at office; best times after 3 p.m. each day or all day Wednesday. Do not call at home.

BROKERING POWER: THE ART OF INFLUENCE

The development of key contacts is an important step toward having reliable sources of communication with your partners. However, the key contact is there chiefly to stimulate initial awareness and respond "on a moment's notice" to your call for assistance at critical decision points. In addition to your key contact, you must build a broad base

for influencing the opinions and decisions of your partners. You must ask who has the kind of influence which can make a difference in the positions that your partner takes. The following is a list of some of the "influencers" you can recruit:

* Family members and Co-workers-These people can have continual, daily influence. Sometimes, however, their input is so frequent that it may not count heavily with your partner.

* Campaign workers-For elected officials, these people have influence in proportion to the level of responsibility they had in the last election.

* Personal friends-When a knowlegeable and committed personal friend intervenes, it can have significant impact on your partner. However friends are often reluctant to ask for a "favor."

* People who represent other people, e.g., members or officers of organizations or institutions. These people can exert substantial influence directly related to your partners' perception of the number of people represented and the intensity of their interest.

* People with stories to tell, e.g., parents-The form and quantity of influence provided by these people relates primarily to the quality of the content of their message. Always look for sincere, knowledgeable, and articulate people; avoid the angry or the critical.

* Professionals-Knowledge is power. The impact of a well informed professional can be immense, particularly if your partner is already generally supportive of your issue. The sharing of professional knowledge provides your partner with ammunition and makes him/her an enlightened advocate.

REMEMBER:

Power-brokering is a process of working through others to accomplish your objectives.

The timing of the use of influence is an important consideration. Since most major issues will require work by both the executive and legislative branches, avoid starting your power-brokering during or near to the time of a legislative session. When should you exercise your influence?

* Start at least six months prior to the time the decision must be made. This will give your partners enough time to consider, plan, consult, and commit. It is easy to be "too late" to have your issue considered; you can't be "too early."

* It is important to communicate frequently enough to identify yourself with your issue. One goal would be to have your partner think of you each time the issue is raised.

* If your partner comes to identify you with your issue, you must be available for consultation if called upon. You must promptly respond to requests for information if you expect your partner to respond to your issue.

* By three months prior to a legislative session, most legislative members and executive branch leaders have chosen issues to which they will be personally committed. It is better to wait until the next year than to attempt to disrupt your partners' agendas.

REMEMBER:

The longer you and your partners have to accomplish your objective, the better prepared you will be to succeed.

While timing is significant, actions are also important to know what to do. Here are some suggestions for exercising your influence:

* Write letters to your partners. The letters should be brief and well documented. They should require a specific response for a number of reasons. First, the response lets you know whether your message was received and understood. Second, it may reveal your partners' position on the issue. Third, the answer gives you an opportunity to continue another round of correspondence.

* Whenever possible, call for face-to-face meetings which are informative and which call for specific assistance. Personal contact is powerful because it gives you and your partner opportunities to explore both the issue and each other. Always keep such encounters short and to the point and always, always follow up with a written summary of the meeting and thank-you note.

* Getting your partner to see the nature of the problem you wish his/her help in solving can be one of the most powerful tools you have. A well-orchestrated site visit can produce greater influence on the opinions of your partner than almost any other strategy.

* When communicating with your partner, do not use technical jargon. Give your partner ideas in language he/she can use comfortably.

* Make your issue relevant to your partner by describing how it impacts on his/her constituency.

* Do your best to create opportunities for your partner to espouse publically your issue. Invitations to your partner to speak on the subject is an effective way to assure his/her continued advocacy. Be available to assist your partner to

prepare for such speaking engagements.

* Always share the "good press" with your partner. Give a supportive partner public credit for active interest and the benefit of the doubt for future interest. As a power-broker, you are much better off letting your partner take the credit for presenting your issue. Part of your job is to help your partners look good. If you are good at power-brokering, you you will avoid taking credit; always give it to your partner.

* Get to know your partner's assistant and secretary. A good relationship with your partner's staff can assure you of easy access. Without such a relationship, you may have limited or poor access.

One last point: attempt to coordinate your power-brokering with similar local and statewide efforts. Neither you nor your partner should feel like loners. You can frequently find other individuals and groups having similar interests. You may be able to "network" with them to provide additional strength to your common issues.

REMEMBER:

The more involved and informed your partner is in your issue, the more tenaciously your issue will be supported.

Assuming that your issue needs the intervention of both the legislative and executive branch, and assuming that you have appropriately recruited partners, key contacts and other people supportive of your issue, then the time will come when the issue must surface in the legislative arena. One or more of your legislative partners should be responsible for introducing your issue. Below is a set of suggestions for your efforts during a session of the legislature.

* Carefully monitor the progress of your issue. Most legislatures have an information service which will allow any citizen to track the progress of legislation.

  ** Observe the committees to which the issue is referred.
  ** Watch committee agendas to determine when your issue will be heard.
  ** If your issue is referred to a number of committees, then press to have the issue agendaed early in the session, otherwise it may be so delayed that it may never reach consideration by the full legislature.
  ** Through your fellow advocates, maintain a continuous flow of interest directed at both the staff and membership of the committees. Don't push: the monitoring and displays of interest will keep your partners alert to your issue.

* Work primarily with the executive and legislative staff unless a major problem arises.

  ** Your partners are usually so preoccupied with each other during a legislative session that they will not have much time or inclination to review your issue with you in detail.
  ** The staff actually assist in the preparation of agendas. In many cases they manage the information which will reach your partners during a busy session. In a sense, the staff serve as the managers of your partners' work.

* Continually offer information and assistance to your partners and their staffs.

  ** Offer to organize testimony to be presented at committee hearings.
  ** Be fully prepared to testify with little notice, if requested.
  ** Provide sufficient information to make your partners appear knowledgeable.

* Always coordinate your efforts with other advocates. Thus you will expand your monitoring base and sometimes you may be able to receive or give on the spot assistance in pursuit of each other's issue.

* During the session, use your key contacts in emergency situations only. They can lose their effectiveness if they are constantly involved; you can lose them as key contacts if you

overuse them.

After a legislative session, no matter what the outcome of your issue, remember that there is always another need and/or another year. As an advocate/power-broker you have a continuing responsibility to the children you represent to maintain and enhance your partnerships. These suggestions are useful in fulfilling that responsibility.

* Immediately and personally thank your partners for their interest, support, and/or success. Do so in writing with copies sent to your key contacts and fellow advocates.

* If your issue was successful, then keep your partners informed of progress in the program they supported and create opportunities for public expressions of pride and gratitude.

* If your issue was unsuccessful, it may not have been your partners' fault. Sometimes competing priorities and lack of time may have caused the issue to become sidetracked. And sometimes you may have missed an opportunity to do the needed power-brokering. Being a power-broker is a skill learned with practice.

* Never blame your partner for the failure of your issue even if he/she actually recommended or voted against it. You have to consider whether you provided enough information and support to make him/her an effective and committed partner. Then you can choose to renew your efforts with your partner or choose a new one for the next opportunity to raise your issue. There is always next year.

* Under no circumstances should you drop your interest and efforts in support of your issue. If you appear to lose interest, you and your issue lose credibility. The process of power-brokering is a continuous one that demands pragmatic idealism and long-term commitment.

SUMMING UP

Power-brokering is an art and, like any art, requires discipline and practiced skill. Understanding the process is useful, but in developing resources for children with special needs, understanding is not enough. Reading about power-brokering is very much like reading about swimming; you are neither a power-broker nor a swimmer as a result of mastering the concepts and language. You need practice and sometimes you need help. As a person new to power-brokering, you may find that the checklist in the appendix will help you organize your efforts.

There are successful power-brokers at the state level in every state. Find one and volunteer to assist with an issue; the experience will be taxing and time consuming, but worthwhile. The article appended to this workbook is an example of one success of state level power-brokering which continues to help thousands of children with high cost medical needs.

CHECKLIST FOR POWER BROKER
ORGANIZING YOUR EFFORTS

_____ 1. Define your issue.

_____ 2. Propose a strategy to guide your efforts.

_____ 3. Identify the partners-in-power needed to succeed with your issue.

_____ 4. Select your partners.

_____ 5. Identify key contacts for each partner.

_____ 6. Provide information to partners, key contacts, and fellow advocates.

_____ 7. Recruit and organize the partners, key contacts, and fellow advocates who wish to join you in your power brokering strategy.

_____ 8. "Push softly and pray hard."

_____ 9. Assess results.

_____ 10. Follow up with praise of your partners regardless of the result.

APPENDIX A

A POWER-BROKER'S CASE STUDY

REGIONALIZED NEONATAL/PERINATAL INTENSIVE CARE CENTER PROGRAM:

A POLITICAL HISTORY

Gerold L. Schiebler, M.D. and Stephen A. Freedman, Ph.D.

Statewide Interest in High Technology Care

In order to understand the reason for the statewide interest in the regionalized neonatal/perinatal intensive care center system, one must answer the question, "How does politics enter into the process of acquiring high technology care?" While there are number of answers to that question, three emerge as the most significant. They are cost, access, and quality. These three responses interact and cannot be considered separately.

As a matter of pride, many communities may wish to bear the cost of installing high technology care at their local hospitals. Such communities use the argument that access to the desired technology is vital to their constituents' well-being. While the installation of high technology hardware may satisfy the local political desire to have access, questions related to the quality of the application of the technology are frequently omitted from public debate. Typically, when one examines the local access argument, one discovers that initial capital cost is the ascendent public issue. The relationship between long-term costs and maintenance of quality is often obscured.

With the Health Systems Agencies' institutionalization of public debate over the acquisition of high technology health care, the costs/access/quality triad has become a universal argument in support of regionalization. Since the desires of many adjacent communities or closely clustered hospitals to have high technology health care are no longer being honored, regionalization of such care affecting multiple communities takes on a broader political context. Regionalization becomes a political question because it affects multiple communities. As the issue of a regionalized service emerges in the public forum, advocacy groups representing sub-populations which might be excluded from access by geography or costs assert their interests and concomitantly their influence. Government provides the forum for the mediation and negotiation of those interests.

Once government involves itself in the political process, it must develop guidelines for judging the arguments of various interests. In the finest example of such government intervention, guidelines have taken the form of objective standards developed by the professionals

most knowledgeable regarding the proposed technology. Once decisions are made regarding the regional distribution of a high technology service, government becomes the responsible party to assure uniform access and quality.

Regionalized Neonatal/Perinatal Intensive Care Center System-The Model

In 1973, the Division of Children's Medical Services (CMS) was established by an act of the Florida Legislature as the State's lead agency responsible for all publicly supported child health care programs in Florida. At that time, five neonatal intensive care centers existed. They served primarily indigenous populations and were not coordinated. As a consequence, access to this new and important advance in medicine was not uniform. CMS saw the opportunity to assume the responsibility for assuring access for all newborns needing that form of care. Early analysis revealed limited knowledge of the availability of neonatal intensive care services in the larger medical communities. The new leadership of CMS decided to support the state-wide development of the neonatal intensive care unit (NICU) movement by addressing seven desirable improvements.

The first was to stimulate communication among the existing centers. The second was to develop qualitative standards for the evaluation of existing and proposed centers. The third was to develop a State-wide referral system to assure maximal utilization of existing resources. The fourth was to expand access through the development of rapid transportation resources and additional, geographically distributed beds. The fifth was to control cooperatively the development of new NICU's to avoid geographic maldistribution. The sixth was to provide an outreach education program to a wide variety of health care professionals to assure appropriate and timely referrals of infants in need of this new service, and the dissemination of knowledge regarding appropriate community based post-discharge aftercare. The seventh was concurrently to implement an ongoing, independent, longitudinal evaluation conducted by professionals not engaged in the care of the infants.

At the earliest stages of planning, it was apparent that for CMS to solicit the cooperation of the existing centers, an infusion of new financial support was needed. The leadership of CMS approached the exisiting centers to assess their willingness to collaborate on the development of a state-wide program. Once consensus for such collaboration was established, the next step was to secure the financial resources to permit the existing centers to provide the quality and quantity of service consistent with the desired new program.

In order to achieve the desired end, i.e., substantial new resources to support the proposed program, a plan of action was implemented. Since all governmental programs compete with each other for resources, neonatal intensive care had to be made understandable and attractive to the political leadership. Two key arguments were put forth. First and least persuasive was the argument of humanitarian responsibility to avoid the tragic consequences of inappropriately serving sick and premature infants. Second and most persuasive was the

argument that--with a modest investment of support for neonatal intensive care--major existing and future costs could be avoided in the support of services for neurologically and physically impaired citizens of the State.

These arguments were first formally articulated in August of 1973, by Dr. Benjamin A. Johnson, interim Director of the newly created Division of Children's Medical Services (CMS), and Dr. Richard J. Boothby, a neonatal/perinatal intensive care advocate from Jacksonville. As a result of their persuasive skills, the new Secretary of the Department of Health and Rehabilitative Services, O. J. Keller, committed himself to incorporate their proposal as one of his administration's new budgetary initiatives in his 1974 - 1975 Legislative Budget Request. Armed with those arguments, Dr. Johnson and Secretary Keller succeeded in convincing Governor Reuben Askew to propose this new initiative to the Florida Legislature. Under an agreement with the Governor's Office, CMS was to seek a Legislative appropriation of one million dollars.

In November of 1973, the first permanent Director of CMS, Dr. Gerold L. Schiebler, was appointed by Secretary Keller with the concurrence of Governor Reuben Askew. As a condition of his appointment, Dr. Schiebler requested liberal access to both the Secretary and the Governor and his staff during the formative period of the new agency. With that access granted, Dr. Schiebler secured permission to review and revise the proposed 1974 - 1975 Legislative Budget Request. Among the revisions made to the proposal was an increase to $1.5 million in the amount to be sought for the Regional Neonatal Intensive Care Program (RNICC). Among the reasons for the revision was the newly added requirement for a continuing, comprehensive evaluation system to be conducted by professionals other than those engaged in rendering the specialized care. Two senior staff members of the Askew administration assisted in assuring that the revised budget met the high standards required for legislative consideration of such a complex proposal. They were Mr. Joseph P. Cresse, Director of the Division of the Budget, and Mr. A. H. "Fred" Baldwin, Chief of the Bureau of the Budget.

Prior to the 1974 Legislative Session, Dr. and Mrs. Lewis A. Barness hosted a dinner meeting at their home to discuss the proposed RNICC program with Dr. Richard S. Hodes, a physician-legislator whose support was essential to the success of the proposal. Dr. Barness and the other physicians attending the meeting (the late Dr. Louis E. Cimino, Drs. John S. Curran, Gerold L. Schiebler, Donald N. Smith, and Nelson J. Spoto) were asked two critical questions by Dr. Hodes. 1) How much would a fully implemented statewide system cost to operate, and 2) How would the incidence of developmentally impaired children be affected? The responses to those questions were: 1) that an adequate statewide system of neonatal/perinatal (pediatrics and obstetrics) intensive care would cost approximately $20 million at 1973 prices and, 2) that the incidence of developmental impairment should dramatically decrease. As a result of that meeting, Dr. Hodes became the first key legislator to advocate actively for the proposed RNICC appropriation.

It was clear that expectation for additional political support should be focused on key legislators sitting on the appropriate House and Senate committees, especially those legislators representing localities with the existing centers perceived as benefitting most directly by the proposed appropriation. Those centers were located in Pensacola, Jacksonville, Gainesville, Tampa and Miami. During the 1973 Legislative session, the leadership from those five areas was as follows:

Pensacola - Representative Edmund Fortune, Chairman of the Appropriations Committee, House of Representatives;
Jacksonville - Representative Earl Dixon, Chairman of Appropriations Subcommittee on Health and Rehabilitative Services, House of Representatives;
Gainesville - Senator Robert Saunders, Chairman of Ways and Means Committee Senate;
Tampa - Representative Richard S. Hodes, M.D., Chairman of Health and Rehabilitative Services Committee, House of Representatives;
Miami - Senator Kenneth Myers, Chairman of Health and Rehabilitative Services Committee and Chairman of the Ways and Means Subcommittee on Health and Rehabilitative Services, Senate.

The CMS leadership conceded that simply proposing the program and its benefits in competition with roads, education, agriculture, and tourism probably would not yield the desired results. Consequently, that local political action would be necessary to influence those key legislators in favor of the establishment of a regional neonatal intensive care system.

Local individuals involved in the initial planning of the proposed program were encouraged by the Director of CMS to develop an active and ongoing dialogue with the key legislator from their respective areas. The individuals who played a major role in the political activity in support of the proposal were:

Pensacola - Dr. William Reed Bell, Sister Carol Keehan (Administrator of Nursing Services at Sacred Heart Children's Hospital), Dr. Edward R. Westmark, and Dr. John H. Whitcomb;
Jacksonville - Dr. Richard J. Boothby, Dr. R. Donald Garrison and Dr. Richard G. Skinner, Jr.;
Gainesville - Dr. Edmund F. Egan, II, Dr. Donald V. Eitzman, Dr. Gerold L. Schieber, and Dr. James L. Talbert;
Tampa - Dr. Lewis A. Barness, the late Dr. Louis E. Cimino, Dr. John S. Curran, and Dr. Richard S. Hodes (a key member of the Florida Legislature who committed himself to the concept and influenced his colleagues in that body);
Miami - Dr. Eduardo Bancalari, Mr. Lynn B. Clarke (Governmental Liaison to the Legislature for the University of Miami), Dr. William W. Cleveland, and Dr. Robert J. Grayson;
State-wide - Local District CMS Medical Directors, the leadership of the Florida Heart Association (Mr. Henry F. Hunter, Executive Director), the Florida Pediatric Society, the Florida Chapter of the American Academy of Pediatrics, and the Florida Perinatal Association, under the leadership of Dr. Richard J. Boothby.

As a result of the efforts of those individuals and organizations to provide appropriate and timely information to the key legislators cited above, an appropriation of $1.5 million ($300,000 per existing site) was made to Children's Medical Services to support its effort to initiate a State-wide program in neonatal intensive care.

Since the inception of the Regionalized Neonatal/Perinatal Intensive Care Center Program (RN/PICC) political support for the program has continued and expanded. Principal among those key individuals recently providing that support are: in the Executive Branch of Florida's government, Governor Bob Graham and Secretary David H. Pingree of the Department of Health and Rehabilitative Services, and, in the Legislative Branch, Representative Samuel P. Bell III of the House of Representatives and Senator Robert W. McKnight of the Senate. Their support, along with the support many others, have made many substantial improvements in the RN/PICC program and its bases of support.

A few of those outstanding improvements are:

** A requirement for an open, statewide admission policy at all RN/PICC's;
** Establishment of objective standards for facilities and personnel, and for the external evaluation of program outcomes;
** A modification of Florida's insurance laws to require coverage under family health insurance policies of all newborns, from birth;
** A requirement for family health insurance to cover at least $1000 in transportation costs related to access to RN/PICC care;
** Automatic, separate and concurrent coverage under the Medicaid Program for a period of 60 days for all newborns of Medicaid recipient mothers;
** Financial and programmatic support for decentralized stepdown care;
** A grant-in-aid system of funding which assures each RN/PICC of a fixed level of governmental support while permitting the centers to garner and keep all third party payments in amounts up to their actual costs;
** Assurance of government support for transportation, notwithstanding the financial or insurance status of the family;
** Approximately a seventeen-fold increase in state financial support between 1974 and 1982.

Over the past 10 years, continuity of commitment has been manifested by the incumbents of the Office of Director of CMS, Dr. Nicholas Alexiou, Dr. Steve A. Freedman, Dr. Martin L. Schulkind, Dr. Louis B. St. Petery, and Dr. Julia C. St. Petery. Under the current leadership of Dr. William W. Ausbon, those early efforts have blossomed into a state-wide, regionalized neonatal/perinatal intensive care center program involving the authorization of ten regional centers with a budget of more than 25 million dollars.

As a result of implementation of the program the original seven

objectives have been met and morbidity and mortality rates among sick and premature infants in the State of Florida have plummeted below the national average. Florida's regionalized neonatal/perinatal intensive care center system is frequently used as a model by other states in their attempt to secure similar achievement. This system stands as a positive symbol of what can be achieved for children when health care professionals and key legislators commit themselves to a concerted cooperative effort.